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Convention on the Rights of Persons with Disabilities

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Twentieth session

Summary record (partial)* of the 396th meeting
Held at the Palais des Nations, Geneva, on Monday, 27 August 2018, at 10 a.m.

Chair: Ms. Degener

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* No summary record was prepared for the rest of the meeting.

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The meeting was called to order at 10 a.m.

Opening of the session

1. **The Chair** declared open the twentieth session of the Committee on the Rights of Persons with Disabilities.

Opening statement by the representative of the United Nations High Commissioner for Human Rights

2. **Ms. Gilmore** (United Nations Deputy High Commissioner for Human Rights), welcoming participants on behalf of the Secretary-General and the High Commissioner, said that she wished to congratulate the Committee on the tenth anniversary of the Convention, which provided an opportunity for renewed efforts to bridge the gap between the commitments made by States parties and what had been delivered. While the impact of the Committee's work could be measured in a number of ways, none was more important than the extent to which it transformed access to the enjoyment of rights for persons with disabilities.

3. A number of other significant milestones in the area of rights had been reached in 2018, including the twentieth anniversary of the Declaration on Human Rights Defenders, the twenty-fifth anniversary of the Vienna Declaration and Programme of Action, pursuant to which the post of United Nations High Commissioner for Human Rights had been established, and, critically, the seventieth anniversary of the Universal Declaration of Human Rights. The adoption of the Universal Declaration, the product of negotiations between Governments from around the world, had represented a global consensus as to the supreme value of every human being.

4. Context was a key variable in the exercise of human rights. In that regard, the rights of persons with disabilities were of critical importance in the humanitarian, migration and disaster management contexts, as had been expressed at recent forums and conferences and in the proposed Global Compact for Safe, Orderly and Regular Migration. The circumstances of persons with mental health conditions and psychosocial disabilities also deserved particular attention. As the High Commissioner had emphasized, forced treatment, forced institutionalization and segregation should no longer be practised. In that connection, the draft Additional Protocol to the Council of Europe Convention on Human Rights and Biomedicine, concerning Biomedical Research, was a cause for grave concern. With regard to the deprivation of liberty of children with disabilities and the enjoyment of human rights by children with disabilities, including through inclusive education, the joint meetings that the Committee was scheduled to hold with the Committee on the Rights of the Child during the current session were of great importance.

5. In the area of inclusion, it was recognized that the United Nations was one of those systems that must change. The Secretary-General had therefore initiated the development of an action plan and accountability framework for the inclusion of persons with disabilities in the work of the Organization. In addition, the rights of persons with disabilities would be a critical priority for the Office of the United Nations High Commissioner for Human Rights (OHCHR) over the next four years. Leadership and participation by persons with disabilities were essential in transforming discriminatory practices, and the Committee had a crucial role to play in that regard.

Adoption of the agenda (CRPD/C/20/1)

6. *The agenda was adopted.*

Report of the Chair on activities undertaken between the nineteenth and twentieth sessions of the Committee

7. **The Chair** said that Mr. Ruskus had represented the Committee at a side event organized during the thirty-seventh session of the Human Rights Council in connection with World Down Syndrome Day in March 2018 and at an event held at United Nations Headquarters in New York to mark World Autism Awareness Day in April 2018. Mr. Tatić had delivered the keynote speech at a high-level conference on the political participation of

women with disabilities, organized by the Organization for Security and Cooperation in Europe and held in April 2018. She herself had been involved in the preparations for the Global Disability Summit, held in London in July 2018, and had participated in the seventh meeting of the Policy Board of the United Nations Partnership to Promote the Rights of Persons with Disabilities, which had taken place in New York in June 2018.

8. Mr. Ruskus had represented the Committee at a conference in Stockholm in April 2018 organized by Civil Rights Defenders, while Mr. Basharu had participated in a two-day consultation in New York in May 2018, jointly organized by the International Service for Human Rights and the Special Rapporteur on the situation of human rights defenders. The aim of both events had been to build on the momentum associated with the twentieth anniversary of the Declaration on Human Rights Defenders. In that connection, the Committee had been asked to endorse a statement on the important work of human rights defenders. She wished to call on members to respond positively to that request.

9. On 29 May 2018, the Committee had published the report on its confidential inquiry concerning Spain. She wished to reiterate the Committee's call for Spain to establish a national action plan, in consultation with representative organizations of persons with disabilities, in order to achieve inclusive education.

10. A number of Member States had made commitments during the universal periodic review to ratify the Convention. The Committee had sent letters to those Member States encouraging them to step up their efforts to that end.

11. Mr. Basharu had represented the Committee in May 2018 at the thirtieth meeting of the Chairs of the human rights treaty bodies. She wished to highlight a number of matters raised in the report on the meeting, namely: the Chairs' regret at the granting by the General Assembly of additional meeting time to the treaty bodies without the necessary human resources to service the meetings and at the decision to approve only 5 of the 11 temporary posts requested by the Secretary-General for OHCHR; the Chairs' discussion of practices in implementing the guidelines on the independence and impartiality of members of the human rights treaty bodies (Addis Ababa guidelines); and the Chairs' decision to prioritize at their next meeting the consideration of the 2020 review of the treaty body system.

12. A day of general discussion had been held in New York in June 2018 on articles 4 (3) and 33 (3) of the Convention, concerning the participation of persons with disabilities in the implementation and monitoring of the instrument. The event had been well received by the 250 participants, who had included representatives of organizations of persons with disabilities, civil society actors, Governments and United Nations agencies. Given that consultation and involvement of organizations of persons with disabilities were at the heart of the instrument, it was important for such days of general discussion to be held regularly, rather than every two years as was envisaged.

13. She and several Committee members had participated in the eleventh Conference of States Parties to the Convention in June 2018. Seven new members had been elected and would assume their mandates on 1 January 2019; it was pleasing to note that six of them were women. She welcomed the Secretary-General's announcement at the Conference that an action plan and accountability framework would be developed to strengthen mainstreaming of the rights of persons with disabilities throughout the United Nations system.

14. At the Conference, the Committee had held a side event on its draft general comment No. 7 on articles 4 (3) and 33 (3). She wished to express her thanks to the sponsors of the event, particularly the Governments of Germany and Thailand. During the current session, Mr. Buntan would brief the Committee on the activities he had undertaken at the Conference in relation to situations of risk and humanitarian emergencies, which might become the subject of a subsequent general comment. OHCHR would unfortunately no longer able to fund the travel of Committee members to Conferences of States Parties in New York.

15. By way of follow-up to the day of general discussion, stakeholders would have further opportunities during the current session to make statements on draft general

comment No. 7, after which a second draft would be prepared and discussed by the Committee.

16. In June 2018, the Committee had joined the Expert Working Group for addressing women's human rights in the proposed Global Compact for Safe, Orderly and Regular Migration. In July 2018, together with Mr. Basharu, she had attended the sixth meeting of the Group, at which a disability-inclusive statement had been finalized on the gender-related issues that were missing from the final draft of the Compact. She wished to call on members to refer to the statement in dialogues with States parties.

17. The Committee had been involved in preparations for the first International Day of Sign Languages, which would be observed on 23 September 2018. It would dedicate half of its meeting time on the afternoon of 13 September 2018 to that initiative.

18. Following discussion between the Committee and the Committee on the Elimination of Discrimination against Women, a joint statement had been drafted on guaranteeing sexual and reproductive health and rights for all women, in particular women with disabilities. The groundbreaking statement had been adopted by the Committee on the Elimination of Discrimination against Women at its seventieth session; members should consider doing likewise.

19. On 31 August 2018, the Committee, the United Nations Office at Geneva and OHCHR would hold an event to commemorate the tenth anniversary of the entry into force of the Convention. In connection with the anniversary, a report on the Committee's work over the previous 10 years had been prepared and would be published on the Committee's website and in print. It was hoped that an Easy Read version would follow in due course.

20. During the current session, several joint meetings would be held with the Committee on the Rights of the Child, including a dialogue between all the members of both Committees. The meetings would build on the experience of the joint informal working group on the rights of children with disabilities that the two Committees had established in 2015.

21. Following an analysis of previous dialogues between the Committee and States parties, a policy had been developed that would limit the number of Committee members taking the floor during each cluster of questions and the speaking time allocated to each member. The policy would be reviewed by the Committee at the end of the session.

22. The role played by national human rights institutions and organizations of persons with disabilities in frameworks established to monitor the implementation of the Convention was recognized in article 33 (2). She was pleased to note that cooperation between independent monitoring frameworks, including national human rights institutions, and the Committee had improved. For example, the Global Alliance of National Human Rights Institutions (GANHRI) had contributed to the preparation of the Committee's draft general comment No. 7. The Committee had also benefited from the expertise and work of national human rights institutions in the inquiry procedures carried out under the Optional Protocol to the Convention.

23. The Committee had engaged with national human rights institutions and independent monitoring frameworks from 15 of the 20 States parties that would be discussed during the current session and in the tenth pre-sessional working group. It had received reports from 13 such institutions, while 8 would be participating in private briefings concerning country situations. In addition, national human rights institutions from three of the seven countries under review would participate in the dialogues between State party delegations and the Committee. She would encourage such institutions, along with independent monitoring frameworks, to continue their active involvement in the work of the Committee and to build their monitoring capacity.

Submission of reports by parties to the Convention under article 35

24. **Ms. Rinaldi** (Secretary of the Committee) said that Ireland had ratified the Convention on 20 March 2018, bringing the total number of States parties to 177. Tajikistan had signed the Convention on 22 March 2018. The number of States parties to the Optional Protocol remained unchanged at 92. Since the previous session, OHCHR had

received six initial reports under the Convention, from Ghana, Jamaica, the Netherlands, Togo, Tuvalu and Viet Nam, making a total of 116 reports. The Committee had considered 67 State party reports, which meant that 49 reports were still awaiting consideration.

Cooperation with other United Nations bodies, specialized agencies, organizations of persons with disabilities and other competent bodies

25. **Ms. Devandas Aguilar** (Special Rapporteur on the rights of persons with disabilities) said that, in March 2018, she had submitted a report to the Human Rights Council (A/HRC/37/56) addressing the issue of legal capacity law reform. The report, which was aimed at informing States parties about the measures they should consider taking to implement article 12 of the Convention, highlighted good practices and the positive progress made towards full recognition of the legal capacity of persons with disabilities around the world. In October 2018, she would be presenting a report on the right to health to the Third Committee of the General Assembly.

26. Following her visits to the Democratic People's Republic of Korea and Kazakhstan, she would be issuing reports on those countries, which would shortly be available on the OHCHR website. Confirmed invitations to undertake country visits in 2019 had been received from Botswana, El Salvador and Norway. Canada was also expected to issue an invitation.

27. In April 2018, she had held an expert meeting with notaries to discuss the role they played in implementing article 12 of the Convention. A similar meeting would be held with judges in November 2018.

28. As part of the process of establishing a system-wide approach within the United Nations to the rights of persons with disabilities, she had been asked to undertake a baseline review of the current situation in that regard. The review was intended to guide the efforts of the Inter-Agency Support Group on the Convention to develop a policy action plan and accountability mechanisms for adoption by the United Nations System Chief Executives Board for Coordination in 2019. It included an institutional assessment of the action being taken by United Nations agencies to respond to the needs of persons with disabilities. An analysis of the measures being carried out by the Secretariat to promote the rights of persons with disabilities — in conjunction with their representative organizations — was also being conducted, with particular attention being paid to the situation of United Nations staff members with disabilities.

29. She welcomed the fact that the Committee was working on a draft general comment on the participation of persons with disabilities in the implementation and monitoring of the Convention. In that connection, she wished to invite the Committee to consult her report on the right of persons with disabilities to participate in decision-making (A/HRC/31/62), issued in 2016. Lastly, she was grateful to the Committee for engaging in discussions with other treaty bodies on such issues as the rights of children with disabilities. Those discussions were necessary to ensure that the highest standards of human rights protection were afforded to all.

30. **Mr. Chávez Penillas** (Office of the United Nations High Commissioner for Human Rights) said he was pleased that the Committee was considering drafting a general comment on article 11, which addressed situations of risk and humanitarian emergencies. The Inter-Agency Standing Committee on Post-War and Disaster Reconstruction and Rehabilitation had established a task team charged with drawing up guidelines on humanitarian action for persons with disabilities. The guidelines were expected to be adopted in 2019. Given the fact that a number of different stakeholders would be responsible for implementing the guidelines, it was essential to establish a coherent implementation framework. If the Committee decided to proceed with the general comment, it would be advisable for it to consider both disaster and conflict situations.

31. He wished to encourage the Committee to make submissions on the reports that OHCHR would be issuing on article 26 of the Convention, on habilitation and rehabilitation, and on article 8, on awareness-raising. In addition, it should send a representative to participate in the Human Rights Council's annual half-day discussion on the rights of persons with disabilities in March 2019. OHCHR was committed to supporting

efforts to establish a system-wide action plan on the rights of persons with disabilities. It would help the Office in its advocacy work with stakeholders around the world if the Committee could provide clear definitions of the human rights-based approach to disability and of the principles of the Convention.

32. **Ms. Löw** (United Nations Entity for Gender Equality and the Empowerment of Women (UN-Women)) said that the annual meeting of the Inter-Agency Support Group on the Convention had been hosted by UN-Women in March 2018 during the sixty-second session of the Commission on the Status of Women. During the meeting, the Secretary of the Committee had suggested that the agencies participating in the Group could increase their cooperation with the Committee by proposing themes for future general comments and responding to calls for submissions concerning draft general comments and input to bilateral or thematic meetings with United Nations agencies and departments to be held during the current session of the Committee.

33. Although the membership of the Group had increased from 8 to about 25, not all members were equally engaged and such engagement was often restricted to disability focal points. There was thus a need for more entities to become actively involved in the work of the Group, including at the highest organizational levels.

34. Accessibility and reasonable accommodation remained major challenges to the full and effective participation of persons with disabilities. Although the United Nations system had made some progress in that regard, such progress remained uneven within and across entities. The best results had been achieved when there had been leadership from the highest level, accompanied by funding and accountability mechanisms.

35. Progress also tended to be made by working with stakeholders towards a common goal. For example, the Inter-Agency Support Group's working group on article 11, which was co-chaired by the United Nations Children's Fund and OHCHR, was contributing to the inclusion of persons with disabilities in humanitarian action through active participation in the related Inter-Agency Standing Committee task team.

36. The Inter-Agency Support Group welcomed the decision to pursue system-wide action and accountability with regard to the inclusion of persons with disabilities. The Group's working group on a system-wide action plan was taking steps to support the implementation of the decision. At the end of May 2018, a meeting had been held with the co-chairs of the Inter-Departmental Task Force on Accessibility to explore possibilities for collaboration to that end. The United Nations system had a unique opportunity to mainstream the rights of persons with disabilities in all their diversity, in all aspects of life and at all levels. The Group stood ready to support that process and looked forward to the active participation and contribution of all United Nations entities.

37. **Mr. Muylle** (Chair, Committee on Victim Assistance under the Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Anti-Personnel Mines and on Their Destruction) said that the States parties to the Anti-Personnel Mine Ban Convention had recognized that what was referred to as victim assistance covered such broad matters as disability, development and human rights. Most of those States parties had also recognized that the assistance they provided to victims of landmines should encourage the development of services, infrastructure and policies that addressed the rights and needs of all persons with disabilities, regardless of the cause of the disability. One recently defined priority was to ensure that victim assistance was made an integral part of national policies and plans focusing on broader areas, such as the rights of persons with disabilities, health, education and employment.

38. The Committee on Victim Assistance encouraged the Committee to adopt a general comment on article 11, which provided a bridge between the Convention on the Rights of Persons with Disabilities and the Anti-Personnel Mine Ban Convention and other international disarmament conventions; a general comment would help clarify how those instruments complemented one other and how they differed. If a decision was made to draft such a general comment, the Committee on Victim Assistance would gladly share the relevant lessons it had learned.

39. For the Committee on Victim Assistance, activities planned for 2018 included a two-day meeting on victim assistance in November. He hoped that representatives of the Committee on the Rights of Persons with Disabilities would be able to contribute to the meeting. The Committee on Victim Assistance was also working with the Implementation Support Unit for the Anti-Personnel Mine Ban Convention to convene stakeholder dialogues on victim assistance in Iraq and Uganda, two countries with significant numbers of landmine survivors. As part of the dialogues, representatives of organizations involved in disability affairs and victim assistance would come together to discuss issues such as how to bring victim assistance under the umbrella of the Convention on the Rights of Persons with Disabilities. In addition, a global conference on victim assistance was planned for 2019; the participation of the Committee on the Rights of Persons with Disabilities in the conference would add considerable value.

40. The States parties to the Anti-Personnel Mine Ban Convention recognized that the assistance they provided to landmine survivors should be provided in accordance with human rights law, and the victim assistance community was aware that the Convention on the Rights of Persons with Disabilities was an overarching instrument enshrining the rights of persons with disabilities, including those disabled by landmines. The Committee on Victim Assistance looked forward to further cooperation with the Committee and other entities providing support to the parties to the Convention on the Rights of Persons with Disabilities.

41. **Mr. Trömel** (International Labour Organization (ILO)) said that ILO worked to promote the employment of persons with disabilities, in the private sector in particular. The ILO Global Business and Disability Network facilitated a number of national initiatives in that regard. An employment network had recently been established in China, for instance, and the establishment of another was planned in India. Such networks contributed significantly to the changing of attitudes towards the employment of persons with disabilities, including in developing countries, where there was often little expectation that such persons could find decent employment.

42. ILO also continued to work with other entities on social protection issues. One of its aims was to help promote the design of social welfare programmes that encouraged persons with disabilities to work rather than simply to collect benefits. In cooperation with the Washington Group on Disability Statistics, ILO continued making efforts to improve the collection of statistics on the employment of persons with disabilities. In addition, ILO, together with the Organization for Economic Cooperation and Development, was contributing to the development of policy guidelines for the employment of persons with disabilities. The guidelines would be adopted at a meeting of the Group of 20, a forum of finance ministers and central bank governors of developing countries, to be held in Argentina in September 2018.

43. ILO had been working on disability issues for many years. The team that focused on those issues was small, but ILO was nonetheless better off in that regard than many other United Nations agencies. It was thus excited to be co-chairing the working group responsible for establishing the system-wide action plan and accountability framework that were being developed, in part, to remedy the results of the years of relative neglect of disability issues in the United Nations system.

44. The United Nations System-wide Action Plan on Gender Equality and the Empowerment of Women, under which annual reporting was required, would serve as a model for the development of the disability action plan and accountability framework. He looked forward to discussing ways of cooperating with the Committee in the development of the plan and the framework, which were to be unveiled in March 2019.

45. **The Chair** said that she wished to assure the representative of ILO that Committee members who were in a position to contribute to the development of the system-wide action plan and accountability framework would do so.

46. **Ms. McCoy** (World Health Organization (WHO)) said that the programme of work of WHO, agreed by member States in 2017, had a strong focus on disability. The objectives of the WHO Global Disability Action Plan 2014–2021, which structured much of the Organization's disability-related work, included removing barriers to health services — for

example, by tackling discrimination in health-care settings — strengthening rehabilitation and collecting data.

47. Guidance, training and capacity-building resources provided by WHO were already changing practices in mental health care in a number of member States. In addition, WHO was gathering evidence for the provision of community-based mental health services that responded to people's needs, supported recovery and promoted autonomy and inclusion. It was also rolling out guidance on strengthening the health system to provide rehabilitation services. In addition, the development of measures to facilitate the inclusion of rehabilitation in universal health coverage was under way.

48. WHO was helping member States ensure the availability of the assistive devices they had defined as priorities. It was also working with them to facilitate the collection of high-quality disability data, in large part through a model disability survey developed in partnership with the World Bank. A short version of the survey could be included in other surveys. Improving data collection facilitated efforts to monitor progress towards the Sustainable Development Goals and the implementation of the Convention.

49. Building on a commitment to respect international norms and standards for the realization of the right to health, WHO had recently become one of the joint leaders of a new United Nations task team whose mission was to support countries in making human rights norms a central component of their efforts to ensure that no one was left behind. Activities in that regard included a planned meeting with the secretaries of the human rights treaty bodies to explore new methods of cooperation.

50. **Ms. Halil** (World Intellectual Property Organization (WIPO)) said that, in its activities in the field of copyright, WIPO focused on increasing access to knowledge and educational opportunities for the 253 million persons worldwide who were blind or had print disabilities. The Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled was the legal framework for that work. The Treaty, which had entered into force in September 2016, allowed the production and cross-border transfer of accessible books. It was implemented by the Accessible Books Consortium, a public-private partnership led by WIPO. The goal of the Consortium was to increase the number of books worldwide in accessible formats.

51. The activities of WIPO in that connection were strategically aligned with the disability-inclusive 2030 Agenda for Sustainable Development. They were geared to support the achievement of Sustainable Development Goal 4, on inclusive and quality education for all, and were consistent with articles 9 and 24 of the Convention, on accessibility and education. Since 2014, the Consortium had set up projects to provide training and assistance in accessible book production in 12 countries. It had also funded the production of educational materials. The Consortium's Global Book Service enabled libraries located in contracting parties to the Treaty to search or make requests for accessible digital books without further authorization from copyright holders, while a library-to-library service allowed participating libraries to supplement their collections with works from those of their counterparts in other countries at no charge.

52. In addition, the Consortium encouraged publishers to produce books in accessible formats from the outset. All United Nations agencies were encouraged to sign the Charter for Accessible Publishing, which had been developed to help ensure that books were, as the Consortium put it, "born accessible". States, for their part, were encouraged to become contracting parties to the Treaty and to facilitate the involvement of their national libraries in the Consortium's Global Book Service.

53. **The Chair** said that, in its dialogues with States parties, the Committee invariably encouraged those that had not yet ratified the Marrakesh Treaty to do so.

54. **Ms. Rinaldi** (Secretary of the Committee), reading a statement on behalf of Ms. Sharif, Executive Director of UN-Habitat (United Nations Human Settlements Programme), said that UN-Habitat was committed to making cities inclusive, not least by placing the rights and dignity of persons with disabilities at the forefront of its work. Urbanization generally led to greater opportunity, but rapid, chaotic urban growth had detrimental effects, and public spaces, buildings and transportation in most cities and towns

could often be inaccessible to persons with disabilities, who were thus unable to enjoy their rights and live as full members of their communities.

55. UN-Habitat aimed to uphold the rights of persons with disabilities in all its programmes and initiatives, including by building the capacity of government authorities, communities and other relevant stakeholders. At Habitat III (United Nations Conference on Housing and Sustainable Urban Development), UN-Habitat had worked with disability experts and communities to help ensure that future urban development, guided in part by the New Urban Agenda, was more inclusive of persons with disabilities. In addition, UN-Habitat promoted housing policies that allowed vulnerable groups, including persons with disabilities, to exercise their right to adequate housing. Its other activities included encouraging Governments to provide affordable access to public spaces and to transport, education and health services and to ensure that those services were accessible to all.

56. **Ms. Rudolf** (Global Alliance of National Human Rights Institutions), speaking via video link, said that, in view of their complementary roles in promoting and protecting the rights of persons with disabilities, her organization and the Committee had established a unique, long-standing and fruitful partnership. The rights of persons with disabilities were one of the priority areas of the GANHRI strategic plan, and the organization was committed to continuing to support the work of member institutions and the Committee in advancing those rights. In February 2018, GANHRI had dedicated its annual conference to the role of national human rights institutions in monitoring the Convention. The conference had been the occasion of the first annual meeting between the Committee, national human rights institutions and national monitoring frameworks, and had provided an opportunity to exchange good practices and lessons learned in monitoring the implementation of article 19 of the Convention, on living independently and being included in the community, and also in ensuring the meaningful participation of persons with disabilities.

57. The joint declaration adopted as the outcome document of the meeting identified concrete steps for moving forward with the collaboration between the two bodies. They included: establishing a follow-up group comprising representatives of the Committee and national human rights institutions to develop a common framework for monitoring article 19; advocating for improved data collection and disaggregation to ensure informed and effective policymaking; developing and maintaining a repository of good practices in monitoring the Convention; continuing to strengthen the capacity of organizations of persons with disabilities; and calling for international cooperation that enhanced and promoted the role of national human rights institutions and independent monitoring frameworks.

58. In May, GANHRI had contributed a written submission on the Committee's draft general comment No. 7, reflecting the views and experiences of national human rights institutions across regions. In June, at the eleventh Conference of States Parties to the Convention, GANHRI had co-organized a side event to explore areas for strengthened multi-stakeholder cooperation in following up on the joint declaration. It had also participated in the event on draft general comment No. 7 and had convened a caucus meeting of national human rights institutions to discuss ways of strengthening collaboration among them on the rights of persons with disabilities. GANHRI had received crucial support from the International Disability Alliance (IDA) in the organization of its annual meeting and follow-up activities. It looked forward to hearing the Committee's views on how to move forward on the joint declaration.

59. **Ms. Quan-Chang** (International Disability Alliance) said that her organization was grateful to the Committee for its openness to including civil society organizations in all of its procedures and the value it attached to the expertise and views of persons with disabilities themselves. The day of general discussion on draft general comment No. 7 had provided an opportunity for a diverse range of persons with disabilities and their representative organizations to contribute their opinions. IDA was confident that the Committee would be able to include a variety of input in the final text of the general comment, which it hoped might be adopted at the end of the current session. It was aware, however, that some issues remained to be resolved, notably concerning the inclusion of family members as part of representative organizations. IDA considered that they were a

relevant support to persons with disabilities, particularly in low- and middle-income countries, where the majority of persons with disabilities resided, and must be seen as such.

60. IDA called on the Committee to ensure that it was fully inclusive of all persons with disabilities, leaving no one behind. Persons with disabilities who were lesbian, gay, bisexual or transgender or had another sexual or gender identity must be included as active stakeholders in all organizations of persons with disabilities and consulted, in line with articles 4 (3) and 33 (3), and the Committee should take them into account in its concluding observations and in future general comments and views.

61. IDA welcomed the Committee's active engagement during the Conference of States Parties to the Convention, in particular its statement on the need to give consideration to gender balance in elections. IDA saluted States parties that had committed to restoring a significant number of women experts to the Committee in 2019 and was hopeful that the message would be kept in mind in future, as gender balance and diversity in general were key principles in human rights and should be applied to all United Nations mechanisms and procedures.

62. While IDA was aware of restrictions related to the preparation and adoption of future general comments, it wished to stress the importance — in view of current global geographical, social and political phenomena and movements — of considering a general comment on article 11 of the Convention, on situations of risk and humanitarian emergencies. Persons with disabilities were particularly vulnerable, and little or no humanitarian work was aimed specifically at them. A general comment by the Committee would provide guidelines for States on how to incorporate article 11 into their policies and practices. IDA strongly encouraged the Committee to continue including recommendations about article 11 in its concluding observations.

63. IDA wished to reiterate its serious concern regarding the advanced stage reached by the draft Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Biomedical Research, the provisions of which clearly contradicted the human rights standards set forth in the Convention. In the concluding observations and lists of issues to be adopted during the current session and in the tenth pre-sessional working group, the Committee should request States parties that endorsed the Additional Protocol to withdraw their support. It should also send a clear and strong statement to the Council of Europe.

64. Several issues relating to the rights of children with disabilities needed to be addressed. In particular, IDA would welcome follow-up to the joint initiative between the Committee and the Committee on the Rights of the Child to update the latter's general comment No. 9 on the rights of children with disabilities; such follow-up should be aimed at harmonizing the general comment with articles 7 and 19 of the Convention, the Committee's jurisprudence in its concluding observations and its general comment No. 5 (2017) on article 19. IDA also looked forward to the outcome of the work to harmonize standards with the Committee on the Elimination of Discrimination against Women and, in particular, to the issuing of the groundbreaking joint statement on the rights of women and girls with disabilities.

65. **The Chair** thanked IDA for its support in organizing the day of general discussion and the side event at the Conference of States Parties.

66. **Ms. Swenson** (Inclusion International) said that her network, which represented persons with intellectual disabilities and their families around the world, was also a member of IDA and stood in solidarity with the previous remarks. The Committee's general comments had triggered very important discussions over the past year on key topics such as independent living, equality and non-discrimination and now participation. It was crucial for those discussions to be accessible to everyone and for the participatory processes to be made easier to understand, including through the provision of more plain language and easy-to-understand materials.

67. A fully inclusive model of participation would serve as an example to communities, where persons with disabilities still faced many barriers to participation. The most significant barrier was the denial of legal capacity and of the right of persons with

disabilities to make their own decisions, which prevented persons with intellectual disabilities from participating in public life and employment and affected personal matters such as marriage. It also violated their collective right to form organizations of self-advocates, legally recognized on a basis of equality. In addition, too many people in institutions had little or no opportunity to raise their voices and be visible on public platforms. People living in rural areas were also more likely to be excluded from participating in society.

68. It was important to take account of families, who were a valued part of organizations of persons with intellectual disabilities, and not to replicate the exclusion they already faced in the community. Families were the main source of support for persons with intellectual disabilities, especially persons with complex support needs and those who did not communicate in typical ways. The argument against including families was based mostly on the experience of some persons with disabilities who had been treated badly by family members or who had not been supported to gain independence. Of course, it could not be denied that there were problems. However, Inclusion International strongly believed that the way to overcome them was not by excluding families but by giving a voice to those who supported independent living and human rights. The voice of a family member did not substitute for the voice of a person with an intellectual or cognitive disability; rather, in most cases, a family member was a mediating force between the person with a disability and an unhelpful or dismissive environment. While family members could not be considered persons with disabilities, nor were they third parties, as the Committee clearly recognized in its general comment No. 5 on article 19. Families played a unique role that should be recognized and valued.

69. It must also be ensured that families, who faced discrimination and increased economic and social stress, were up to the task of providing sustaining and empowering family environments for persons with intellectual disabilities. Organizations of such persons advocated for families to have access to the support and services they needed and helped them understand human rights, build self-advocacy and engage in progressive ways of supporting their children throughout their lives. Inclusion International was a united network of self-advocates and families working together for inclusion. It urged the Committee to ensure that general comment No. 7 guaranteed that all persons could participate in implementing the Convention and in the monitoring process.

70. **The Chair** said that, while it was true that there was a lack of accessible documentation in the United Nations generally, with the support of the United Nations Office at Geneva, the Committee had produced 12 core documents related to the Convention in Easy Read format, which would be posted on its website shortly.

71. **Mr. Kofmel** (Autistic Minority International) said that his organization had decided not to make a written submission on draft general comment No. 7 because the call for submissions had given the impression that the contributions of organizations of persons with disabilities would not be considered individually in the context in which they had been made. The situation of organizations run by and for autistic persons was, however, very different from that of other organizations of persons with disabilities, and any suggestions they might make on the text of the draft would be meaningless if taken out of the context of autistic realities and references. His organization was concerned about the increasingly prescriptive nature of the Committee's calls for input, particularly with regard to format and content, which made it very difficult to provide a deep narrative account of autistic life. Providing submissions that reproduced paragraph numbers and proposed specific amendments to the wording of a draft might be achievable for professional disability advocates, but not for autistic volunteers and most other grassroots activists, persons with intellectual disabilities or children with disabilities. The practices of the Committee should set a better example in terms of inclusive consultation.

72. The holding of the day of general discussion during the Conference of States Parties to the Convention had prevented representatives of organizations of persons with disabilities from attending owing to the overly restrictive accreditation requirements. Autistic persons struggled with organizing themselves on account of their actual or perceived impairments and disabling barriers erected by others, which meant that most autistic-led groups were very informal and entirely self-funded, often operating through

social media without any formal structures or documentation. Frequently, autistic-led groups were transnational, with people organizing online around a shared language, and they were not registered with the authorities. As a result, autistic persons were excluded from national and international cross-disability umbrella bodies and national reporting coalitions, and their issues were ignored in alternative reports submitted to the Committee. Even where national autistic-led organizations existed, they were almost always excluded by other disability groups in favour of organizations of parents of autistic children, which were considered easier to work with and attracted all the funding for autism, even though they had fundamentally different views and goals.

73. The cross-disability paradigm to which the Committee adhered perpetuated the systemic exclusion of entire groups of persons with disabilities. His organization called on States parties and umbrella bodies and coalitions to work and consult with autistic persons themselves. If there were no formal autistic-led organizations, it was better to involve informal groups and networks or individual autistic self-advocates rather than parents and non-autistic adults. States parties should provide autistic self-advocates with technical and financial support to establish more formal organizations but should allow the autistic persons themselves to decide what level of formality was appropriate for them. When autistic people submitted information to the Committee outside the framework of national coalitions, it should be easier for them to obtain speaking time during country briefings. His organization would welcome more curiosity from Committee members about the situation of autistic persons. Why, for example, had no autistic person ever been invited to speak at a day of general discussion? General comment No. 7 needed to cover and affirm the organizational forms that were experienced and preferred by autistic people themselves and not those to which they were expected to conform if they wanted to be included and consulted.

74. **The Chair** said that that the Committee was committed to the principle of leaving no one behind, including autistic persons. For that reason, it had decided to offer a further opportunity for discussion of draft general comment No. 7 that afternoon. It would welcome the views of Autistic Minority International on how to improve the draft general comment, as well as any proposals for new methods of consultation.

The discussion covered in the summary record ended at 12.05 p.m.